

# Perceptions of people living with Parkinson's disease: a qualitative study in Iran

**Mohammad Ali Soleimani, Farideh Bastani, Reza Negarandeh, Ryan Greysen**

Mohammad Ali Soleimani, Assistant Professor, Social Determinants of Health Research Center, Qazvin University of Medical Sciences, Qazvin, Iran; Farideh Bastani, Professor, Department of Geriatrics Nursing, School of Nursing and Midwifery, Iran University of Medical Sciences, Tehran, Iran; Reza Negarandeh, Professor, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran; Ryan Greysen, Assistant Professor, UCSF Division of Hospital Medicine, University of California, San Francisco, USA

[bastani.f@iums.ac.ir](mailto:bastani.f@iums.ac.ir)

**P**arkinson's Disease (PD) is a progressive neurologic disorder that has a major effect on a patient's health and quality of life (Playfer, 2002; Muslimovic et al, 2008). The main symptoms of PD are tremor, rigidity, bradykinesia, and postural instability (Olanow et al, 2009). The PD prevalence rate in Iran is 2 per 1000; this rate increases 10 fold for patients over 65 years (2 per 100), and as of 2013, Iran has an estimated 160 000 people with PD (PWPD) (Shahidi, 2012; Soleimani et al, 2015).

PWPD experience progressive decline in motor function. As PD progresses, the disability often worsens and can have a significant negative effect on health-related quality of life (Schrag et al, 2000). Previous research has shown that the progression of PD over time often leads to decreased quality of life resulting from disruption of activities of daily living, loss of employment, disruption of body image and self-esteem and

increased psychological distress (Schrag, 2006; Hirayama et al, 2008; Muslimovic et al, 2008).

PD can also cause neuropsychiatric disturbances that vary from mild to severe. This includes disorders of cognition, mood, behavior, and thought (Jankovic, 2008). Cognitive disturbances can occur in the initial stages of the disease and sometimes prior to diagnosis, and increase in prevalence with disease duration (Caballol et al, 2007; Jankovic, 2008). Memory is affected, specifically in recalling learned information (Caballol et al, 2007). Mood and behavior alterations are more common in PD without cognitive impairment than in the general population, and are commonly present in PD with dementia (Soleimani et al, 2016).

Although there is currently no cure for PD, medications, surgery, and multidisciplinary team management can provide relief from the symptoms (Bronstein et al, 2011). Palliative care is often required in the final stages of the disease when all other treatment strategies have become ineffective. The aim of palliative care is to improve the quality of life for the PWPD and those caring for him/her. The main issues with regard to palliative care in the community are whether adequate care can be provided; reducing/withdrawing medication therapy to lower the side effects of drugs; and making end-of-life decisions for the patient as well as family caregiver, other relatives, and friends (The National Collaborating Centre for Chronic Conditions, 2006).

The costs of PD are high. The annual cost in the UK is estimated to be between £449 million and £3.3 billion, while the cost per patient per year in the USA is around USD 10 000, with the total burden around 23 billion dollars (Findley, 2007). The largest share of direct cost comes from inpatient care and nursing home services, while that from medication is substantially lower. Indirect costs are high, owing to reduced productivity and the burden on caregivers. In addition to economic costs, PD reduces the quality of life of those with the disease and their family caregivers (Findley, 2007). In Iran, there is limited evidence about the cost of treatment, but the largest costs are likely related to laboratory tests for diagnosis and

## ABSTRACT

**Aim:** This study explores the primary concerns and perceptions of patients living with Parkinson's disease (PD). **Method:** This was an exploratory qualitative study. A purposive sample of 17 patients with PD who were attending a hospital outpatients' neurology clinic in Iran were recruited. Study data were collected through semi-structured interviews and analysed using the conventional qualitative content analysis approach. **Findings:** We identified the 'fear of becoming disabled' as a primary concern in these patients. This concern affected the physical, emotional, mental, and social aspects of their lives. The 'fear of becoming disabled' fell into four categories, including progressive physical disability, mental alteration, decreasing social connectedness, and self-change. **Conclusion:** The study results showed that older adults with PD face a number of challenges in self-care. In addition, the 'fear of becoming disabled' was the main concern of patients with PD, particularly in late stages of the disease.

## KEY WORDS

- ◆ Parkinson's disease ◆ content analysis ◆ qualitative study
- ◆ family caregiver ◆ Iran